Letting babies die

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Prolonging neonatal life

The paradox that medicine's success breeds medicine's problems is well known to readers of the *Journal of Medical Ethics*. Advances in neonatal medicine have worked wonders. Not long ago, extremely premature birth babies, or those born with very serious health problems, would inevitably have died. Today, neonatologists can resuscitate babies born at ever-earlier stages of gestation. And very ill babies also benefit from advances in neonatal intensive care. Infant lives can be prolonged. Unfortunately, several such babies will not survive for long whatever is done for them. Others will live to leave hospital, but face severe health problems. Doctors have gained the ability to prolong neonatal life. But should they always do so? This question is central to the recent report of the Nuffield Council on Bioethics, *Critical care decisions in fetal and neonatal medicine*.[1] In many quarters, the report received a very positive response, commended in *The Lancet* as ''thoughtful, sensitive and sensible'' and welcomed by the premature baby charity BLISS. Critics attacked on both flanks. The report goes too far—ushering in a culture of ''throw away babies''. Or it does not go far enough—failing to endorse the Dutch precedent to sanction active neonatal euthanasia.

TOO FAR?

One of the key recommendations of the report is that guidelines be developed in relation to the institution of intensive neonatal care. It is these guidelines, which have been savaged by some parts of the media. The BMA called them ''blanket rules'' smothering clinical discretion. The guidelines on resuscitation at birth apply to babies born at the borderline of viability, that is, at or before a gestational age of 25 weeks 6 days. The earlier the baby is born, the lower are the chances that he/she will survive to leave hospital. Before 21 weeks 6 days, none of the published studies record that a baby survived to leave hospital. The working party did know of one instance of a baby born at exactly 21 weeks 6 days who is now thriving. The EPICure study that followed cohorts of premature babies born in 1995 found that just 1% of babies born between 22 weeks and 23 weeks lived to go home. At 23–24 weeks, 11% survived, rising to 26% at 24–25 weeks and 44% at 25–26 weeks. Subsequent studies suggest better survival rates from 23 weeks. A study in Norway showed 16% of babies surviving at 23–24 weeks, 44% at 24–25 weeks, and 66% at 25–26 weeks. Survival is only part of the story. The EPICure study shows that of the children still living at age 6, half of those born at 22–23 weeks have moderate or severe disabilities, as do 63% of babies born at 23–24 weeks, 50% of survivors from 24–25 weeks and 40% born at 25–26 weeks. These figures must be seen in context. Children with disabilities due to premature birth are but a small proportion of the total number of children with disabilities in the UK.

The statistics are only statistics. The question that any parent is likely to ask when a decision must be made whether or not to resuscitate their baby is— what will happen to my baby? Sometimes the only honest answer a doctor can give to that question, is ''I don't know''. Many reasons might be advanced to urge giving the baby the benefit of the doubt, to resuscitate the infant and see how they progress. Natural instincts might suggest that parental love will, and should, demand that a baby is given any chance of life, however small. Sanctity of life could be invoked to prioritise prolonging life.

The working party, which drafted the Nuffield Report included people from very different backgrounds, holding diverse personal and philosophical positions on the sanctity of life. Support for guidelines, which do not always demand prolongation of life, was unanimous. What do the guidelines say? First, every baby delivered showing signs of life must be examined by an experienced paediatrician. Gestational age estimated during pregnancy can be wrong. The guidelines go on to recommend that where a baby is born before 21 weeks 6 days, attempts to resuscitate a baby should only take place within a clinical research study approved by a research ethics committee and with informed parental consent. Resuscitation should not be the norm for babies born between 22 and 23 weeks, unless the parents, after being fully informed of the available evidence, request resuscitation and reiterate that request. At 23–24 weeks, the degree of uncertainty about the baby's prospects is such that parental views should take precedence. From 24 weeks, the presumption should be for resuscitation, unless parents and clinicians have agreed that, in the light of the baby's condition, it is not in his or her best interests to admit the baby to intensive care.

The guidelines undoubtedly suggest that some babies should not be offered aggressive intensive care. Is this ''butchering'' babies or treating newborn life as of lesser value than the lives of older children or adults? We trust not. Few insist that when life can be prolonged for however a short time, it always must be. What the baby, older child or adult is entitled to, morally and legally, is appropriate care. Neonatal intensive care is invasive and burdensome. A baby may be subjected to 200 or so intrusive and painful procedures in one fortnight. He or she is isolated from the love and warmth of their family, and deprived of the care that should be the birthright of any newborn. When insisting on treatment imposes an intolerable burden on the baby, such treatment becomes inhumane.

However, the difficulty with extremely premature babies is both the uncertainty of outcome and the inability of the baby to make any choice for itself. The Nuffield guidelines emphasise the importance of the parental voice. The ideal remains a ''partnership of care''. In most cases where consensus is not achieved, the parents' view takes precedence. So why advise against resuscitation below 22 weeks? Why have any sort of time frame? On currently available evidence, intensive care before 21 weeks 6 days is experimental. A baby resuscitated at this stage is highly unlikely to benefit. What is learnt about the baby may benefit others. That knowledge may be valuable, but must be measured against its cost to the baby, and parents who agree to allow doctors to attempt resuscitation must understand that their baby will almost certainly die. Between 22 and 24 weeks, in that era of uncertainty, the views of the parents, whose bond with the baby already exists, and on whom the baby is so profoundly dependent, have precedence. But will they speak for the baby, or for themselves? We acknowledge that parents have interests separate from those of their babies. The needs of other children, the parents' own well being cannot be put out of mind. Those interests are not necessarily in conflict with

the baby's interests. The welfare of any child is inextricably bound up with the interests of their family. The baby's interests take priority because it is their very life that is at stake. However, the baby's interests cannot be properly assessed without taking some account of others' interests too.

NOT FAR ENOUGH?

Uncertainty of outcome may lead doctors and parents to agree to start intensive care. The baby does not do well. Doctors conclude that after all their prospects of survival are poor and/or there are serious, irremediable impairments. Continuing invasive care is no longer in the baby's best interests. The report concludes that there is no moral distinction between never instituting intensive care and later withdrawing such care. Yet we unreservedly reject the precedent set in the Netherlands in the Groeningen Protocol. Doctors should not be permitted to take active steps to end newborn life. Wrong headed and inconsistent, argue both proponents of neonatal euthanasia and some opponents of abortion. If obstetricians can end fetal life up to delivery, how is neonaticide different?

The working party endorsed birth as a significant threshold for moral as well as for legal judgments. We did so while acknowledging that many people will see human life as starting much earlier. But for our part (whatever our personal views on fetal status) birth marks the point at which a baby enters the world and is separate from its mother, and can be cared for without intruding on the mother's bodily integrity.

Some people will see deliberately ending a life as no different morally from allowing it to end. For those critics, we should have followed the Dutch example and permitted active steps to end the life of the newborn; for others what we recommend is already just as bad as the Dutch rules and should be condemned out of hand for that alone.

Doctors and parents do see a real and huge difference between ending treatment that only prolongs a terrible life, and giving a lethal injection. We felt it right to respect the feelings of those most intimately involved in decisions about premature babies and who may want the opportunity to spend time caring for a dying baby. And there is a problem of consistency—if we can take a decision to end the life of a baby why should we not also take decisions to end the lives of older children or adults who cannot speak for themselves? Allowing neonatal euthanasia opens the door to non-voluntary euthanasia.

We suspect that a report which attracts such diverse views is probably doing something right. We have tried to start an honest debate about these issues. If premature babies, parents and doctors benefit in the long term, then, and only then, will we know that the report has achieved its objectives.

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REFERENCE

1 http://www.nuffieldbioethics.org (accessed 12 January 2007, The authors were respectively the Chair and a Member of the Working Party that drafted the report).

Neonatal care

End of life decision-making in neonatal care

Carolyn April, Michael Parker

Critical care of neonates

The recently published report of the Nuffield Council on Bioethics, *Critical care decisions in fetal and neonatal medicine*, is a valuable contribution to the discussion of decision making in the critical care of neonates. Drawing upon medical evidence, the working party highlights the many practical difficulties arising in neonatal care and by setting out clearly the nature of the ethical and other issues arising in this area of medicine, and their relationship with neonatal development, the resulting report has the potential to lead both to improved practice and to better informed communication between doctors and families when they face difficult decisions about how best to treat very premature babies. Based on medical evidence, the working party sets out guidelines on decision-making about the resuscitation of babies born before the gestational age of 25 weeks and 6 days, dividing this period into four chronological periods: before 21 weeks and 6 days when resuscitation should normally only take place within the context of a research project; between 22 weeks and 23 weeks when resuscitation should not normally be carried out unless the parents request it; at 23 or 24 weeks when parental views should take precedence; and, after 24 weeks when resuscitation should be the norm unless not in the child's best interests.

There are several practical ethical difficulties with this aspect of the advice. To what extent, for example, does the paediatric assessment of the child, intended to play a role in decision-making about the appropriateness of resuscitation, itself depend on the initiation of resuscitation? To what extent is it reasonable and humane to expect parents to take full responsibility for making decisions about resuscitation between 23 and 24 weeks? On what grounds is it acceptable to attempt to resuscitate a baby <21 weeks and 6 days for a research project, but not when the parents request it for other reasons? Nevertheless, despite these difficulties, and although some members of the British Medical Association have attacked the guidelines as too restrictive and undermining of professional judgement, they have the potential, in our view, to lead to the development of a greater degree of agreed good practice and thereby to constitute an important contribution to neonatal care.

Judging by the media coverage of the report, the issue attracting the most attention as well as the most controversy concerns the ethics of active euthanasia in neonatal care. This controversy arises in part from a request by the Royal College of Obstetricians and Gynaecologists, London, UK that the working party present a discussion on whether active euthanasia should ever play a role in neonatal critical care. The report does take a strong position on the issue and ''unreservedly rejects'' the